

Notes from Neurological Alliance meeting 7th May 2020

**Present**; Chair Becky Duff (MS Society), Vice Chair Tanith Muller (Parkinson’s UK Scotland), Stephanie Fraser (Cerebral Palsy Scotland), Craig Stockton (MND Scotland),Victoria Wareham (Dystonia UK), Sharon Kane (Funding Neuro), Georgina Carr (Neurological Alliance England), Iain Morrison (MS Revive Support), Morna Simpkins (MS Society), Ian Williams (Quarriers), Andy Wynd (Spina Bifida Hydrocephalus Scotland), John Eden (Scottish Huntington’s Association), Anissa Tonberg and Rona Johnson (Epilepsy Scotland), Lynn Stewart (My Aware), Elinor Jayne (Sue Ryder), Gill Dickson (PSP Association), Shirley Maxwell (Epilepsy Connections), Ewan Dale (ME Association), Katie Rigg (MSA Trust)

**Issues arising for organisations and communities**

* Significant issues for families with children with neuro conditions. Clinically they are managing the best they can.
* However, huge pressure is being felt with the additions of home schooling, possible siblings at home, working from home and taking on full caring responsibilities (with no respite, therapies, limited ‘hands on’ support).
* One member reported that families were getting a lot of calls from the professionals who worked with their children but this in itself was becoming burdensome.
* There are huge issues around the impact of lockdown (rather than the impact of Covid now). People feeling very isolated, huge dip in mental health and wellbeing.
* Some cognitive symptoms mean than there are people who don’t understand why family/friends/support workers are no longer visiting and this is causing a flare in challenging behaviours. Some members reported that there has been an increase in domestic abuse, safeguarding and child protection calls to their support services.
* Video and telephone services work in the short term, and in the absence of no alternative. They are not a long term, permanent alternative to face-to-face for the majority of people with neurological conditions. One member gave an example of a blocked catheter being missed on a virtual assessment, resulting in a painful UTI going undetected for several days. Professional staff had feedback that it’s difficult to assess virtually, but even more difficult to treat/support.
* As we move into the recovery phase for services, need to be aware that people have been just living with their problems and holding off contacting health services. This means they may end up presenting with far worse/progressed conditions than we would typically see. Members were concerned that some deterioration may not be recoverable.
* There was a shared concern about what is happening to people who aren’t ‘online’. Particularly those with cognitive impairments, elderly, financial problems etc. These people were the most vulnerable/at risk to begin with and now there’s a sense that they are withdrawing. There’s a reduction in engagement (reflected in helpline calls etc.) at the same time as an increase in need.
* Members who are service providers reported that they had closed/stopped face to face services. Many were now considering how to safely restart these services.
* Transitions in care have been paused. E.g. paediatric services and adult services not linking, and are in very different positions.
* Harm 2 group-those who will come to harm due to prolonged isolation - solutions for this group are being considered by SG.
* Rehabilitation group has also been set up-led by Karen McDonald (lead AHP for SG)
* Some people had cancelled their care packages in fear of people coming into their homes and potential Covid risk. This was with a short-term view and is not sustainable especially when people have ongoing high levels of care need. Now that it’s apparent that the risk and restrictions are going to be ‘live’ longer term, people are struggling to get their care packages reinstated.
* People struggling to get the therapies and equipment they need.
* The suspension of face to face social activities peer support groups was seen as driving isolation for individuals and families. Many organisations were moving activities and groups online. One member reported that they had actually reached different people by delivering their sessions virtually and were looking to continue this alongside their face to face sessions.
* One member reported that their organisation were in a reasonably healthy funding situation, largely because the majority of their funding came from restricted sources and funders had been willing to adjust these restrictions.
* Clinical trials-many of these have been paused and there will be a restart cost involved. One member talked about a trial that will now need to be rehomed, and the challenges that come with that (it’s probable it won’t now go ahead).
* One member report that there had been some positive stories of people who have learned to cope with isolation, loss of income etc. and who are now helping others. Some people with epilepsy are reporting fewer seizures.

**Key Messages from members**

* Virtual services work in the short term, and in the absence of any alternative. They are not a long term, permanent alternative to face-to-face for the majority of people with neurological conditions. Virtual could be seen as first contact/triage for some but there has to be the option of face to face at the next stage and for ongoing support. Can there be a role for the third sector to support this triage approach?
* Family carers are under huge and unmanageable strain with full time caring responsibilities, potentially children to care for and holding down jobs from home.
* Financial implications for individuals. Many already on furlough leave or reduced hours, alongside increasing care costs/financial implications on being at home all the time (e.g. heat and eat). Benefits systems are also slow to react, so people are accumulating debt.
* Financial implications for statutory services-NHS has (understandably) overspent on Covid response, how does this circle get squared? Implications for other services post-pandemic. How do we protect the promise of investment in neurological services through the framework for neurological conditions?
* What’s happening with diagnosis/testing of neurological conditions?
* What the NHS are feeding back to Government is not necessarily the real picture that people are experiencing. Need to have patient experience evidence.
* Recovery phase-how do we get face to face services (statutory and third sector) back up and running? E.g. when and how does physio happen under social distancing? How can we gather data on the impacts of ‘not treating/delayed treatment’ as part of these services reopening?
* Still issues with those who feel they should be shielding but have not been identified as part of the shielding group and very limited support for those in the wider vulnerable (flu jab) group, especially as the Scottish Government’s helpline may be experiencing problems.
* Patient initiated reviews-there is some indication that many services will take this approach. How appropriate is this for neurological conditions? Members felt it was not helpful for those with cognitive and mental health symptoms, poor health literacy or those who otherwise lack insight into their condition. We have often found that those most in need of services are last to come forward and ask for them.

**Questions for members**

1. Are people reporting changes to their care packages and routines? Have packages been reduced out of choice (e.g. people not wanting carers in the home) or because services have been withdrawn?
2. How well are virtual/remote services working? Has there been examples of where this has been beneficial or where things have been missed because not face to face?
3. Is the SG’s 0800 number working for those who need support (but aren’t in shielding group?)

**State of the Nation Report/Campaign**

**Key Issues to address**

* Impact on condition control/self-management
* Impact on condition regression
* Access to specialist knowledge
* Mental health deterioration
* Financial insecurity
* Impact of isolation (not seeing family, friends, support services)
* Impact on carers/family now in full time caring role (alongside other pressures)
* How should the model of care for those with neuro conditions look in the future? Opportunity for NAS to stratify and inject ideas.
* Helpful to include direct quotes from people affected if possible.

**What we know so far**

* Epilepsy Scotland-have been conducting a survey since the start of lockdown. Around 100 people have responded. Half reported that they had seen an increase in seizures. A third had specialist appointments cancelled. One firth reported that they had not been able to have prescriptions filled. Lack of specialist knowledge was causing real issues, one example being a person who felt they had been left to decide themselves wither or not to increase their medication.
* Epilepsy Connections- One member report that there had been some positive stories of people who have learned to cope with isolation, loss of income etc. and who are now helping others. Some people are reporting fewer seizures - they feel safe at home and the stress of going out has been taken away, also some people now have family members on furlough at home and feel less stressed for not being alone. However, others are reporting more seizures and we are currently investigating 2 reports of a particular treatment being denied as it is delivered by injection and their practice nurses have reportedly refused to administer injections. Some people are concerned about going out alone in case they have a seizure outside, and we have one report of an adult and their carer being told they both couldn't access a supermarket together despite explaining their situation.
* The UK MS register are currently conducting a survey about Covid 19 and MS and how the subsequent restrictions are impacting on people with MS. First findings due in a couple of weeks.
* Scottish Huntington’s Association have surveyed their members. They have found people are feeling isolated and anxious. The full time caring responsibilities are really taking a toll and people are deeply concerned about their financial situation, with many already on furlough leave or reduced hours.
* CerebralPalsy Scotland are sending a similar survey out this week or early next week, with data expected in a couple of weeks’ time.
* Parkinson’s UK Scotland also have data on the issues impacting their community and are supporting a longer term survey on the impact of Covid 19.
* Spina Bifida Hydrocephalus Scotland have surveyed their members and can provide data on the issues impacting their community.

**Update from Neurological Alliance of England**

* Significant disruption to routine service. There has been regional variation with this.
* BME groups have been disproportionally impacted by pandemic
* The ability to detect neurological issues early has been impacted.
* There were examples of diagnosis being done over the phone. Staff not trained to do this from a wellbeing point of view for patients, so this causing significant stress all round.
* Redeployment has happened at different rates across specialist services. E.g. nurses were very quickly redeployed
* Concerns around the availability of ventilation support
* People are waiting longer to get medical help, so are going into hospital far worse.
* Neuro Alliance are looking at hospital data (emergency admissions/discharge time/prescribing etc.) to get a picture of what’s happening
* Significant disruption to neuro rehab. Rehab packages being reduced or removed.
* NHS England-reviewing what they have learnt from Covid response
* Post-Covid people are showing neurological symptoms. We don’t know enough yet but could cause strain on services in the future.
* Impact on the third sector-Neuro Alliance have done a survey of their members. They have seen a significant increase in demand and a significant drop in income. The Government support has not been adequate to deal with this to date.
* Big priority of Neuro Alliance has been to connect members-set up the neuro Covid 19 resource forum.
* Now developing their policy recommendations.
* There have been examples of good collaboration, with local authorities and commission managers having weekly planning meetings. How we retain this in recovery/renewal phase.